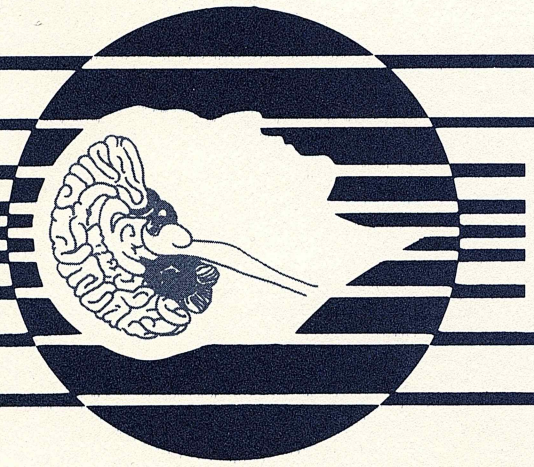
PROPOSED SERVICE DELIVERY SYSTEM

FOR

REHABILITATION OF

MISSOURIANS WITH HEAD INJURY



MISSOURI HEAD INJURY ADVISORY COUNCIL

Service & Program Definitions

STATE OF MISSOURI

OFFICE OF ADMINISTRATION

Missouri Head Injury Advisory Council

P.O. BOX 809
JEFFERSON CITY, MISSOURI 65102
(314) 751-9003

July 9, 1986

Dear Colleague:

Enclosed is a report entitled "Proposed Service Delivery System for Rehabilitation of Missourians with Head Injury: Service and Program Definitions" prepared by the Missouri Head Injury Advisory Council. The report was prepared in response to Executive Order 85-6 which instructed the council to study and make recommendations regarding additional rehabilitation programs, transitional living facilities and community programs for Missourians who have sustained traumatic brain injury.

In carrying out its duties, the members of the Missouri Head Injury Advisory Council studied current programs serving survivors of head injury and discovered that many programs provide similar treatments using different program labels and vice versa. Prior to making any recommendations regarding a state service delivery system, the council developed definitions in order to have a common vocabulary necessary to develop programs.

It is anticipated that our proposed service system and program definitions will be further refined and defined over the years as we all learn more about the treatment and rehabilitation of survivors of head injury.

Meanwhile, please feel free to contact the council at the above address should you have any questions or suggestions.

Sincerely,

Senator Edwin L. Dirck
Chairman

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May, 1986

Missouri Head Injury Advisory Council
Missouri Office of Administration
Division of General Services
Post Office Box 809
Jefferson City, Missouri 65102

PREFACE

It has been estimated that nearly 10,000 Missourians annually suffer head injury which physically disable and mentally impair some of them a lifetime. Two-thirds of the victims of head injury are males between the ages of 15 and 25. Fifty percent of all head injuries are caused by motor vehicle accidents. The remaining 50 percent are caused by sports and recreational accidents, falls, industrial accidents, assaults and weapons.

During the summer of 1984, a legislative Joint Interim Committee on Head Injury conducted statewide public hearings with assistance from the Missouri Association of National Head Injury Foundation. Testimony pointed to, among other issues, the inadequacy of the state service delivery system to address the unique needs of survivors of head injury and their families.

Following recommendations made by the legislative Joint Interim Committee on Head Injury, Governor John Ashcroft created under Executive Order 85-6 the Missouri Head Injury Advisory Council. In the Executive Order, the Governor charged the group to make recommendations regarding appropriate entry points for persons with head injury seeking services from state agencies. The order also instructs the council to study and make recommendations regarding additional rehabilitation programs, transitional living facilities, and community programs for persons who have sustained traumatic brain injury.

The members of the Missouri Head Injury Advisory Council have subsequently investigated current programs serving persons with brain injury in Missouri and discovered that many programs provide similar treatments under different labels. In the same vein, different programs provide treatments using the same label. It was clear that recent growth in the treatment of brain injury has resulted in a lack of common vocabulary. Prior to making any recommendations regarding programs, the council believed it was necessary to establish a common vocabulary to describe different types of programs.

In order to provide common terminology to aid program development and to facilitate the most effective use of existing programs, the council generated specific descriptors of the most common treatment programs for persons who have sustained traumatic brain injury. Whenever possible, the descriptors have specified the nature of the program, goals, and staffing. These descriptions are intended to provide a basis for future discussion and the eventual development of comprehensive descriptors which form the nucleus of programming throughout the state.

The Missouri Head Injury Advisory Council has defined "head injury" or "traumatic head injury" as a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition.

OVERVIEW

Part of the challenge of providing adequate care for persons who sustain traumatic head injury is the diversity of needs after injury. Post-injury care can range from full-time nursing care to community reintegration. The order in which services are used can also vary; some people will move from acute medical care into community integration while others may require extended periods of nursing care before they benefit from rehabilitation. Many persons require more than one type of treatment simultaneously. Thus, service systems must be flexible but also allow for the most frequent progressions. Most often, after traumatic brain injury, the victim goes from acute medical care to rehabilitation. This first rehabilitation, or **Acute Brain Injury Rehabilitation,** focuses on physical and gross cognitive deficits. Those who evidence significant cognitive impairment may go directly from the acute medical setting to structured placement in a facility providing a high level of nursing care. Even after the rehabilitation, some persons are still unable to manage their daily needs and are discharged to a nursing facility. However, those who progress in rehabilitation may be discharged to a variety of situations depending upon their level of functioning. Those requiring more rehabilitation, particularly on advanced daily living, interpersonal, or vocational skills, may be discharged to a post-acute rehabilitation program or **Functional Living Rehabilitation** program. These programs focus on teaching skills necessary for community reintegration while creating an environment that allows rehearsal of these skills. Typically, these programs are less like hospitals and are similar to the living standards to which the person will return.

Often, brain injured persons will live in some type of transitional program as they return to the community. In a **Transitional Living** program, they live in an environment replete with trained staff who provide support and structure. The participants also spend part of their day in the community in job situations. Transitional Living programs may be part of Functional Living programs or may be separate. After completing the Transitional Living program, persons with brain injury may be ready to return to the community. Even after completing the rehabilitation programs described, survivors of head injury may continue to need support and structure at both home and work. **Community Support Services** help them and their families by providing a wide array of services such as psychological therapies, transportation, legal services, or respite care.

The range of services required to treat traumatic brain injury is vast. The service delivery system envisioned by the council is flexible. Rehabilitation of persons who have sustained traumatic brain injury is based upon small steps emphasizing increased demands until the person's maximum level of independence is established. Services are utilized to help brain injured persons maintain that level of independence until they are ready to move to the next level. While return to community living is the ultimate goal, it must be recognized that the level of functioning will vary and require differing support services.

The following pages describe Acute Brain Injury Rehabilitation, Functional Living Rehabilitation and Transitional Living programs and those services which have been defined under the heading of Community Support Services.

ACUTE BRAIN INJURY REHABILITATION

This intensive rehabilitation program provides comprehensive, goal directed rehabilitation services. The program is designed to prevent and/or minimize chronic disabilities while restoring the individual to the optimal level of physical, cognitive, and behavioral functioning. The program is designed to serve persons sustaining traumatic head injury. The rehabilitation program should be carefully coordinated and implemented as soon after onset of injury as is medically feasible.

Program Structure

Setting

1. The service should be delivered on an inpatient basis with specifically designated beds for the rehabilitation of persons with brain injury including availability of private rooms for individuals demonstrating behavioral or medical needs.

2. Treatment space should include the availability of a distraction-free individual treatment area.

3. Provisions should exist for insuring a safe and secure environment consistent with the unique behavioral and cognitive limitations of this population.

Staffing

1. There should be designated staff assigned to serve patients with brain injury. While the staff may serve other patients, its primary involvement and expertise should be in the area of brain injury treatment.

2. One individual should be designated as administrator of the unit.

3. Overall direction and medical management of the program should be provided by a designated physician experienced in the rehabilitation of brain injury.

4. Staffing should include:
   a. Seven days per week, twenty-four hours per day physician coverage.
   b. Medical management of the individual by a single primary physician with specialized training in the rehabilitation of brain injury.
   c. Medical consultation of other specialties such as physical medicine and rehabilitation (PM&R), neuro-surgery, othopedics, surgery, urology and ophthalmology should be available.

Treatment/Rehabilitation

1. While the acute rehabilitation program may serve several acute hospitals, there should be a formalized relationship with the local acute hospitals providing neurotrauma care. The relationship should provide for timely transfer, mutual consultative services, inservices, and sharing of treatment protocols.

2. Assessment, coordinated program planning, and direct services on an intensive, regular, and continuing basis should be provided by a primary team with special interest training in brain injury rehabilitation. The core team should be specifically designated to serve persons with brain injury and should include the following disciplines:
   a. Physician
   b. Rehabilitation nursing
   c. Physical therapy
   d. Occupational therapy
   e. Social services
   f. Speech and language therapy
   g. Clinical psychology or neuropsychology
   h. Therapeutic recreation

3. Diagnostic services should be available or readily accessible on a regular basis, including:
   a. Radiological services, including CT scan
   b. Electrodiagnostic services, including EEG, EMG, and evoked potentials
   c. Laboratory services
   d. Neuropsychological testing

4. Each individual admitted to the unit must have a treatment plan specifying medical and rehabilitation goals. The treatment should be reviewed on a regular basis by the treatment team, the patient, and the patient's family or significant others. Goals should be specific and obtainable.

5. A formally organized program should be provided for education support and advocacy for patients and their families.

Other Program Considerations

1. There should be an adequate volume of admissions sufficient to support a comprehensive, categorically designed program. It is suggested that approximately ten beds and/or thirty admissions annually are necessary to maintain a viable acute brain injury program.

FUNCTIONAL LIVING REHABILITATION

Functional living rehabilitation provides intensive rehabilitation with goal directed services to persons who have either completed acute rehabilitation or who have no major acute rehabilitation needs. The population served includes persons who have sustained traumatically acquired non-degenerative head injury. Emphasis in this program is on functional living skills, adaptive strategies for cognitive, memory, or perceptual deficits, and appropriate interpersonal skills.

Program Structure

Setting

1. Service may be delivered on an inpatient (residential) or outpatient (day program) basis. The volume of admissions should be sufficient to support a comprehensive, goal directed program aimed at increasing functional living skills.

2. There should be specifically designated space and/or beds alloted to the program. Substantial distraction-free space should exist.

Staffing

1. The program should have a designated director. There should be designated staff assigned to serve patients with brain injury. The staff's primary involvement and expertise should be in the area of brain injury.

2. The program should have an established formalized consultation relationship with a physician.

Treatment/Rehabilitation

1. The program should have an established, formalized relationship with acute rehabilitation programs. The relationship should provide for timely transfers, mutual consultative services, information exchange, inservice education, and sharing of common treatment protocols.

2. Assessment, coordinated program planning, and direct services on an intensive, regular, and continuing basis should be provided by a core team with specialized interest, training, experience, and expertise in brain injury rehabilitation and should include the following core disciplines:
   a. Clinical psychology or neuropsychology

b. Occupational therapy
c. Learning skills/education
d. Life skills specialist
e. Rehabilitation counselor

3. The program should have an ongoing method for evaluating neuropsychological, medical, behavioral, and vocational/educational status of the participant.

4. The program should have a method for assessment of prevocational skills and a plan for providing structured activities.

5. A formally organized treatment program should exist. A treatment plan, which is frequently revised, should be developed for each individual shortly after admission to the program.

6. The program should have supervised components directed toward increasing independence.

7. There should be a method for follow-up on discharged patients.

Other Program Considerations

1. There should be a formalized relationship between the facility and local vocational and/or educational programs which allow the facility to provide:
   a. Inservice training on the sequelae of brain injury.
   b. Application of testing and program performance with persons who have sustained traumatic brain injury.
   c. Specific recommendations for educational, behavioral, and compensatory strategies that will be necessary for optimal performance in vocational or educational programs.

TRANSITIONAL LIVING

Transitional Living programs provide intensive rehabilitation with goal directed services to persons who have sustained traumatic head injury and who have completed acute and functional living rehabilitation programs or who have no significant need for such services. Emphasis in this program is on living in an independent situation. In this program, participants would typically move from close observation and supervision to independent living with minimal supervision.

Transitional living programs may exist independently or may be part of a larger program. Regardless of the superstructure of the program, each program must meet specific requirements established for that category.

Program Structure

Setting

1. The program should provide safe, accessible housing which allows transition from group living situations to independent living. Housing facilities should include provision for 24-hour supervision.

2. Either the whole facility or specific space within the facility should be designated as belonging to the program. This space should be large enough to allow the teaching of living skills and should be well maintained. Routine inspections by qualified personnel should be conducted to insure that the electrical, sanitary, heating, and cooling systems are functional and maintained.

3. Housing facilities should provide access to all types of facilities necessary for independent living.

Staffing

1. The program should have a designated director. The staff should have expertise in the treatment of brain injury. While the staff may have other obligations, its primary responsibility should be to the program.

Treatment/Rehabilitation

1. The program should have an established formalized relationship with local rehabilitation programs. The relationship should provide for timely transfers and sharing treatment protocols and information.

2. Assessment, coordinated program planning, and direct services should be provided in an intensive and ongoing manner. Members of the core team should be trained to provide the services for which they are responsible.

3. A formally organized treatment program should exist. A treatment plan, which is frequently revised, must exist for each participant. The program should be developed shortly after admission and contain specific treatment goals for the participant.

4. The program should have a formalized relationship with vocational training or on-the-job training programs. This relationship should provide for placement of program participants in job situations which provide job skills.

5. In the event a participant is not suited for vocational training, the program should have a format manner of ensuing training and practice in the use of leisure time.

6. There should be a method for follow-up and coordination of discharged participants.

COMMUNITY SUPPORT SERVICES

Community Support Services provide ongoing or intermittent support to traumatically head injured individuals and their families after rehabilitation. These services may exist independently or be part of a larger program. Such services provide ongoing or intermittent support in the following areas:

Residential

Supervised Living Arrangement is a place of residence that substitutes for the individual's own home or for the home of the individual's family. It should provide environments that are conducive to the development of adaptive behavior, self-help and independent living skills. The residence also should facilitate, to the greatest possible extent, continuity with culturally normative living patterns. It should be located within the community and should include both generic and specialized services.

Structured Residential Placement provides 24-hour care and treatment for those individuals who manifest severe behavior problems. The setting may exist independently or as part of a larger program.

Coma Management Programs may accept such individuals once they are medically stable and attempt to achieve improvement by the use of various stimulation techniques. Skilled nursing care and physical therapy are important elements of these programs.

Employment

Supported Employment refers to a work situation where the conditions for employment in some manner are subsidized or altered to allow the person with head injury to be employed in a competitive or quasi-competitive environment.

Job Coaching refers to the provision of a trained clinician working with both the brain injured person and the employer to facilitate development of appropriate skills in a new job. The job coach works at the employment site to observe and intervene on problem behaviors.

Sheltered Workshop Employment refers to an occupation-oriented facility operated by a not-for-profit corporation, which, except for its staff, employs only persons with a handicap and has a minimum enrollment of at least fifteen employable handicapped persons.

Vocational Assessment is the determination of vocational skills and limitations which allows mainstreaming or sheltered employment opportunities.

Other Types of Services

Day Program maintains the intellectual, emotional, social, vocational, and physical capacity of persons with head injury who are not in a full time school or work program.

Counseling is an individual or a family intervention to provide psychological support, direction, or change with regard to feelings or thoughts elicited or resulting from brain injury.

Family Training is a program of training for family members which provides skills to assist the person with a head injury in the family and outside of the home emphasizing a program of structural activities inside the home. In essence, family members are trained to become their own service providers.

Case Management is an encompassing process which is the link between the client and service delivery system. It is a method that analyzes client needs, assesses area resources in order to provide, procure, purchase, and coordinate services for persons with brain injury. The process must be flexible to allow for the reformulation of service plans relative to changing client needs. It allows clients to remain in their least restrictive environment and foster the concept of normalization.

Protective Services refers to the provision of a system of continuing legal, social, and other appropriate services designed to assist individuals who are unable to manage their own resources or protect themselves from neglect, exploitation, or hazardous situations without assistance from others and to help them exercise their rights as citizens. Assistance is rendered by providing advice and legal processes to safeguard the rights of persons with head injury by assuring that they receive appropriate services and by preventing their abuse.

Crisis Intervention refers to services which are available on an emergency basis and immediately are responsive to family needs.

Respite Care refers to temporary care provided by trained, qualified personnel, on a regular or intermittent basis, to relieve the family of care responsibilities for brief periods. Respite care may be provided in the home or in a centralized location and has as its purpose: (1) the meeting of planned or emergency family needs; and/or (2) the restoration or maintenance of the physical and mental well-being of the client and/or the family.

Evaluation Services provide systematic appraisal of pertinent physical, psychological, vocational, educational, cultural, social, economic, legal, environmental, and other factors for survivors of head injury and their families to determine the extent of limitations caused by the disability and to develop an individual program of services and actions.

Transportation refers to the provision of necessary travel accommodations for persons with brain injury to and from places where they are employed or where they receive other services. Transportation may include the provision of driver's education, adaptive automotive devices, and/or training in the use of public transportation systems.

Recreation may be provided in specialized programs specifically for persons with head injury or in existing community programs.

Home Health Care refers to services which provide skilled nursing visits and personal care services.

Behavior Management Programs address those behaviors that limit an individual's participation in most rehabilitation settings; e.g., destructive behavior to self or others, sexual aggression, and other severe aberrant behaviors.

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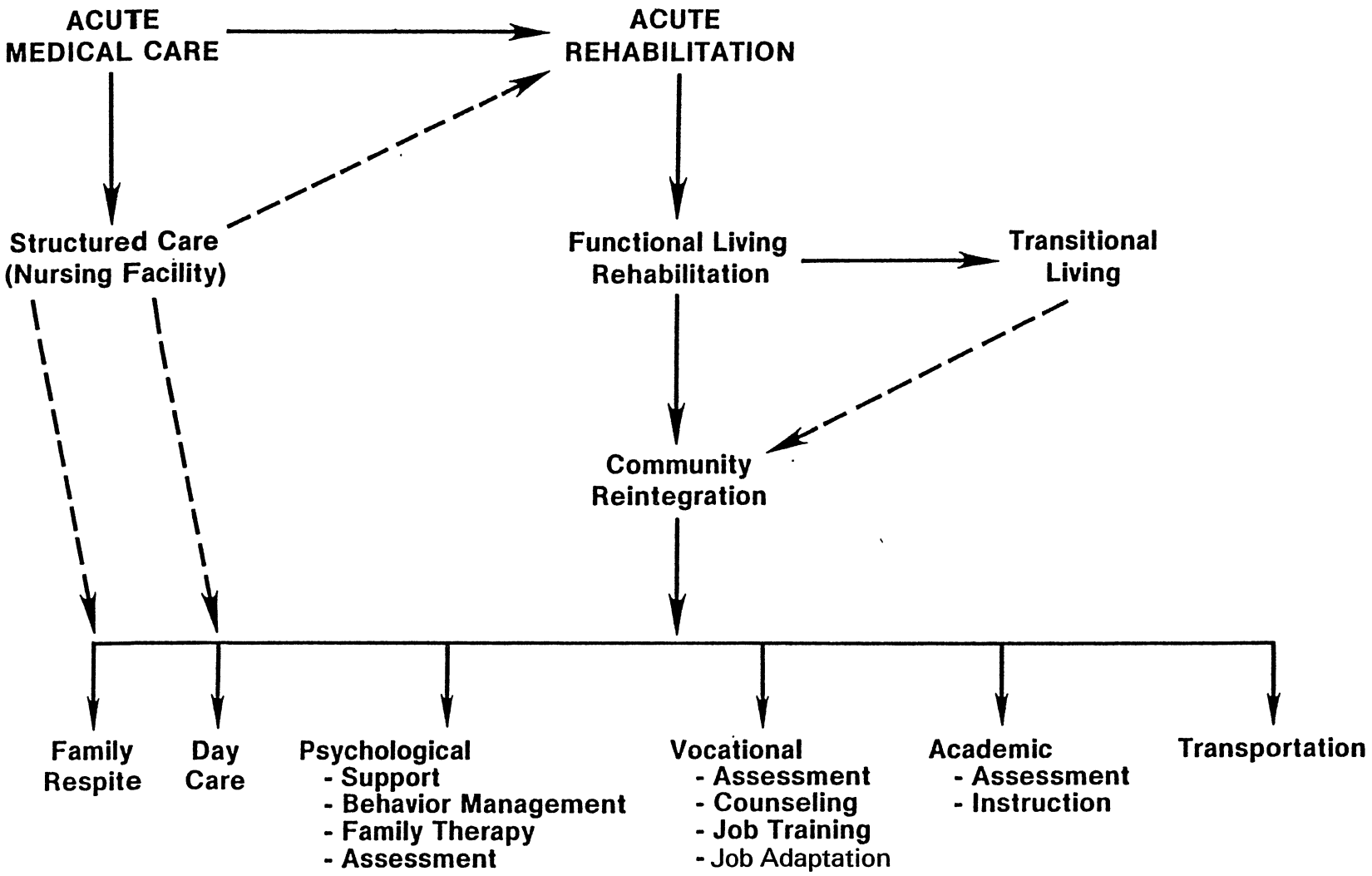

COMPARISON OF THE THREE TYPES OF REHABILITATION PROGRAMS

	Acute Brain Injury	Functional Living	Transitional Living
Setting	• Inpatient with designated beds for the rehabilitation of persons with brain injury • Distraction-free individual treatment area • Provisions for a safe and secure environment consistent with the unique behavioral and cognitive limitations exhibited by persons with traumatic brain injury	• Inpatient (residential) or outpatient (day program) basis • Designated space and/or beds alloted to the program	• Safe, accessible housing to allow transition from group living to independent living with 24-hour supervision • Either the whole facility or specific space within the facility should be designed as belonging to the program
Staffing	• Designated administrator of the unit and designated experienced staff assigned to serve patients with brain injury • Overall direction and medical management of the program should be provided by designated physician experienced in rehabilitation of brain injury • Staffing should include: a. Seven days per week, twenty-four hours per day physician coverage b. Medical management by a single primary physician with specialized training in the rehabilitation of brain injury c. Medical consultation of other specialties such as physical medicine and rehabilitation, neurosurgery, orthopedics, surgery, urology and ophthalmology	• Designated director and designated experienced staff assigned to serve patients with brain injury • Formalized consultation relationship with a physician	• Designated director. Staff should have expertise in treatment of brain injury and although they may have other obligations, their primary responsibility should be to the program
Treatment/ Rehabilitation	• Formalized relationship with the local acute hospitals providing neurotrauma care • Primary team to provide assessment, coordinated program planning and direct services on an intensive, regular and continuing basis	• Formalized relationship with acute rehabilitation programs • Core team to provide assessment, coordinated program planning and direct services on an intensive, regular and continuing basis	• Formalized relationship with local rehabilitation programs • Core team to provide assessment, coordinated planning and direct services on an intensive and ongoing manner

	Acute Brain Injury	Functional Living	Transitional Living
	• Core team specifically designated to serve persons with brain injury and should include the following disciplines: a. Physician b. Rehabilitation nursing c. Physical therapy d. Occupational therapy e. Social services f. Speech and language therapy g. Clinical psychology or neuropsychology g. Therapeutic recreation • Diagnostic services available or readily accessible, including: a. Radiological services b. Electrodiagnostic services c. Laboratory services d. Neuropsychological testing • Individual treatment plans specifying medical and rehabilitation goals • Treatment plan reviewed regularly by treatment team, patient and patient's family or significant others • Provide organized program for education support and advocacy for patients and their families	• Core team should have expertise in brain injury rehabilitation and include the following core disciplines: a. Clinical psychology or neuropsychology b. Occupational therapy c. Learning skills/education d. Life skills specialist e. Rehabilitation counselor • Ongoing method for evaluating neuropsychological, medical, behavioral and vocational/educational status of the participant • Method for assessment of prevocational skill and a plan for providing structured activities • Formally organized treatment program • Individual treatment plan reviewed and revised periodically • Supervised components directed toward increasing independence • Follow-up discharged patients	• Core team should be trained to provide the services for which they are responsible • Formally organized treatment program • Individual treatment plan reviewed and revised periodically • Formalized relationship with vocational training or on-the-job training programs • Formal manner of ensuing training and practice in use of leisure time for those not suited for vocational training • Follow-up and coordination of discharged participants
Other Program Considerations	• Adequate volume of admissions sufficient to support a comprehensive, categorically designed program	• Formalized relationship with local vocational and/or educational programs which allow the facility to provide: a. Inservice training on the sequelae of brain injury b. Application of testing and program performance with persons who have sustained traumatic brain injury c. Specific recommendations for educational, behavioral and compensatory strategies necessary for optimal performance in vocational or educational programs	

APPENDIX

Missouri Head Injury Advisory Council

Senator Edwin L. Dirck, Chairman, St. Ann

David B. Collins, Vice Chairman, Survivor of a head injury and Vocational Rehabilitation Counselor, Lester E. Cox Medical Center, Springfield

Paul R. Ahr, Ph.D., M.P.A., Director, Missouri Department of Mental Health, Jefferson City

Mahlon R. Aldridge, Parent of a child with a head injury, Jefferson City

John F. Allan, Ed.D., Assistant Commissioner, Missouri Department of Elementary and Secondary Education, Division of Special Education, Jefferson City

Michael H. Brooke, M.D., Medical Director, Irene Walter Johnson Institute of Rehabilitation, St. Louis

Caroline S. Castillo, Survivor of a head injury, Kansas City

Donald M. Claycomb, Ph.D., Executive Director, State Council on Vocational Education, Jefferson City

Ben H. Ernst, Assistant Director, Rankin Technical Institute, St. Louis

R. Dale Findlay, Director, Missouri Safety Council, Jefferson City

Judith A. Ferguson, Parent of a child with a head injury, Vice President of State Association Affairs, National Head Injury Foundation, Inc., Richmond

Robert G. Frank, Ph.D., Assistant Professor, Department of Physical Medicine, School of Medicine, University Hospitals and Clinics, University of Missouri, Columbia

Donald L. Gann, Ed.D., Assistant Commissioner, Missouri Department of Elementary and Secondary Education, Division of Vocational Rehabilitation, Jefferson City

Charles H. Goforth, President, UpJohn Health Care Services, Springfield

L. Dennis Humphrey, Ed.D., Professor, Department of Biomedical Services, Southwest Missouri State University, Springfield

Gerald J. Kampeter, Parent of a child with a head injury, Jefferson City

Nancy Koenig, Parent of a child with a head injury, Florissant

Jane Y. Kruse, Director, Missouri Department of Social Services, Division of Medical Services, Jefferson City

Representative Sheila Lumpe, University City

Donald E. McGowan, Safety Director, General Motors - BOC Group, Wentzville Plant, Wentzville

Representative Marvin E. Proffer, Jackson

Thomas M. Sullivan, Deputy Director, Department of Economic Development, Jefferson City

Nathan B. Walker, Director, Missouri Department of Public Safety, Division of Highway Safety, Jefferson City

Senator Harry Wiggins, Kansas City

Lorna Wilson, R.N., Director, Missouri Department of Health, Division of Local Health and Institutional Services, Jefferson City


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